

## **When explanations rest: "Good-enough" Brain Science and the New Sociomedical Disorders<sup>1</sup>**

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*Explanations come to an end somewhere.* – Wittgenstein, *PI* §1

Wittgenstein's opening to *Philosophical Investigations* points to a fundamental crisis in scientific and medical research: When is there enough explanation of a phenomenon to consider it settled and definable? If a cluster of symptoms – say dizziness, itching, extreme fatigue and weakness – afflicts a group of persons working together, what kind of explanation is good enough? Is finding a food they all ate, or common exposure to a rare gas, or a common brain pattern enough to say, "Okay, that is it"? Or is locating a certain gene they all share, or a drug that relieves some of the symptoms enough? What if only four out of five share the characteristic? Or yet again, do we need the entire pathophysiology of each symptom?

The fact that different people answer these questions differently points to the social location of these questions. The very meaning of 'definable illness' and especially the entailments of that definition -- whether a person with symptoms receives help or blame or dismissal -- depend upon who is doing the assessing, where they are doing it from, and within what regime of social good and compassion they are operating. We may not like the implication that a person is sick in one place but not in another, but socially this may be a fact.

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In this paper I begin an ethnographic characterization of what is *shared* across a set of contested fields I call the New Sociomedical Disorders. Under this name, I include Attention Deficit Disorder (ADD), Chronic Fatigue Syndrome (CFS), Gulf War Syndrome (GWS), Multiple Chemical Sensitivity or Environmental Illness (MCS) and to a lesser extent, Post-Traumatic Stress Disorder (PTSD), schizophrenia and depression. Each of these has been and continues to be the object of anthropological, sociological, and psychological studies. Each is very different from the others in terms of history, demographics, and the social location of controversies.<sup>2</sup> Nonetheless, all of these conditions share the following characteristics:

1. They are "biomental": their nature and existence are contested as to whether they are primarily mental, psychiatric, or biological.
2. They are causally undetermined: their etiology is likewise contested as to social, genetic, toxic and individual responsibilities.
3. They are "biosocial": persons having these conditions are organized, coordinated, and feel a kinship based on their shared experience.<sup>3</sup>
4. They are legally explosive: each condition is caught up in court battles, administrative categorization and legislative maneuvering. Disability status, for instance, is haphazardly applied.
5. They are therapeutically diverse: the nature and reimbursement of competing therapies, including alternative medicine is wide open.

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<sup>2</sup> Useful overviews of ADD, also known as Attention Deficit Hyperactivity Disorder (ADHD), include Nadeau (1995) and The Harvard Mental Health Letter (1995). CFS is also known as Chronic Fatigue Immuno-Deficiency Syndrome (CFIDS) and has been studied by medical anthropologists Norma Ware (1993) and Arthur Kleinman (Ware & Kleinman 1992). MCS is also known as Environmental Illness and is thoroughly debated in a special issue of *Toxicology and Industrial Health* (1992). For a history and summary of the many names for this condition, see Miller (1994). PTSD and Depression deserve inclusion because they continue to fulfill each of the seven conditions listed below. These latter two have also been the subject of medical anthropological scrutiny (Kleinman & Good 1985; Young 1995).

<sup>3</sup> The concept of "biosociality" was coined by Rabinow (1992).

6. They are cross-linked: each of these conditions has been linked to the other ones as subsets, mistaken diagnosis, and comorbid conditions.
7. Functional brain imaging is contested: brain scans (PET, SPECT, and MRI)<sup>4</sup> play a significant role in staging the objectivity of each of the first six characteristics for each of these conditions, and is highly contested.

My interest in these disorders is in trying to understand how and why they have come to share these characteristics, and what this sharing implies about the landscape of biomedicine and suffering in the U.S. today. The level of medical, social, legal, scientific and economic disorder implied by these seven characteristics must not be underestimated. Each of these conditions is a serious matter not only for the persons afflicted, but also for the thousands of physicians, researchers, corporations, insurance and administrative agencies having to deal with them. Yet, except perhaps for schizophrenia and depression, very little mainstream biomedical research has been carried out. Fights over definitions, diagnosis, response and prevention depend disproportionately on a small amount of research, much of it underfunded. In the absence of definitive answers, control of the very questions to be asked is also highly contested.

Drawing on studies of each individual illness, my project is to analyze the contested cultural field that helps to shape these illnesses from the outside as sociomedical disorders. By following the ways brain imaging circulates through the various sites of medicine, insurance, the internet and courts, I begin to make explicit how scans and other biological evidence are usually not the final word on these disorders. Instead, they function *locally* as *temporary* resting places for explanations. At stake, even in my ethnographic descriptions, are the status of these brain imaging studies, and further, who has the right or ability to pass judgement on their status. What criteria, for instance, is sufficient to show significant differences between two groups? What method of analysis is good enough? Is PET or SPECT ready yet? I am not attempting to answer these questions here for two reasons. First, there are already *too many answers out there*,

*competing*, and at best I could only echo one of these. Second, the *criteria for evaluation varies by site*. I am therefore trying to track the siting of the questions and the various attempts to frame and reframe the value and significance of different techniques within each site.

In this paper, I will first use the example of a particular contest over Boeing Corporation's role in defining and accounting for MCS in a factory in the state of Washington, to point out the many layers of social control that intersect in these illnesses. I then focus on the key role of brain imaging in these contests, how it comes to be so important and so controversial. I conclude with a discussion of how communities that have gathered around these disorders have become active participants in the both the dissemination of research findings amongst themselves and publicly, and in the activity of research itself. In many cases, including the Boeing story below, the internet has become a crucial medium for the exchange, collaboration, and archiving of information and strategies regarding these illnesses. Where possible, I have provided internet sites for locating these.

## **It's All in Boeing's Head**

*Disputes do not break out...over the question whether a rule has been obeyed or not. People don't come to blows over it, for example. That is part of the framework on which the working of our language is based...*

*'So you are saying that human agreement decides what is true and what is false?' – It is what human beings say that is true and false; and they agree in the language they use. That is not agreement in opinions but in form of life.*

– Wittgenstein, *PI* §240-1

Between 1988 and 1989 at least one hundred workers at a classified Boeing factory had enough symptoms including skin rashes, respiratory tract irritation, memory lapses, and

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<sup>4</sup> PET stands for 'positron emission tomography', SPECT for 'single-photon emission computed

irritability to seek out medical attention.<sup>5</sup> At another plant, working with a known (to Boeing) toxic substance, many workers also came down with similar symptoms. In the worst of these cases, workers developed extreme sensitivity to many chemicals commonly used in cities and homes, necessitating elaborate precautions in terms of lifestyle. On top of trying to live with these symptoms, they also tried to obtain medical attention and diagnosis from their insurer's doctors. Since Washington is a self-insured state, Boeing was their insurer, and therefore Boeing decided what would count as a job-caused condition, as a disability, and as worker compensation. Most of the afflicted workers were examined and told that their symptoms were most likely "in their heads," directly implying that they were at fault for these symptoms, or certainly that Boeing was not at fault. Some women, for instance, were told that they were "just having a bad case of PMS" (Nelson & Worth 1994: 8). As they began to fight these diagnoses, often resorting to outside physicians and researchers, the workers became involved in a much larger struggle over the research and diagnosis of MCS. Two reporters from the *Washington Free Press* summarize the Kafka-esque situation of these workers.

... the furious medical debate surrounding MCS has complicated matters for people who suffer from the condition. Because there's no medical consensus on what causes MCS, or how to diagnose or treat it, the state's "objectivity" test is nearly impossible for MCS patients to pass.

Plus, MCS is not recognized by the international body that categorizes diseases and illnesses. So even if a worker can "objectively" show that workplace chemicals caused him or her to contract MCS, Boeing and the Department of Labor and Industries [L&I] will reject the claim.

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tomography', and MRI for 'magnetic resonance imaging'. See descriptions below.

<sup>5</sup> This account is primarily drawn from the series of four articles by the *Washington Free Press* 5a: (Nelson & Worth 1994) *WFP* "Boeing to Ill Workers: 'It's All in Your Head.'" (archive); (Nelson 1994a) *WFP* "Boeing Story.. Vindication" (archive); (Worth 1994a) *WFP* "Suicide

Making matters still worse, Boeing has a policy of refusing to pay for the tests customarily used by Dr. Gordon Baker and other specialists to diagnose MCS. This is because Boeing and the state Labor and Industries department do not recognize these tests as "objective" ways of diagnosing MCS, which is also not yet recognized by Boeing or L&I (Nelson & Worth 1994a).

As part of the attempt to diagnose MCS, many of the patients sought out SPECT scans (single photon emission computed tomography), a kind of functional brain imaging that produces three-dimensional images of bloodflow. These scans are similar to PET scans (positron emission tomography), but of much lower resolution and are less expensive to produce. There had been some published studies "showing" that SPECT found substantially more "abnormalities" in the brains of MCS patients compared with normal controls. Boeing, as the insurer, however, in most cases refused to pay for the scans and refused to accept the results.

In addition, Boeing, in collaboration with the University of Washington conducted a study led by Dr. Gregory Simon that concluded that MCS patients primarily suffered from psychological problems (Nelson & Worth 1994a: 10; Simon 1993).<sup>6</sup> Other researchers, also funded in part by Boeing, not only argued for the psychological nature of MCS, but also argued against the use of tests such as brain imaging to help diagnose it. For many MCS sufferers as well as some researchers and the *Washington Free Press*, it seemed that potentially critical tests were being excluded *a priori*.

At issue in this struggle is the existence of a syndrome or disease, the definitions of its diagnosis, treatments, and its etiology: Is it? What is it? How can it be treated? What causes it? At stake are legitimization of sick roles,<sup>7</sup> self-respect, research dollars, scientific careers, and

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Solution" (archive); (Worth 1994b) *WFP* "Disunity among the Machinists" (archive); (Nelson 1994b) *WFP* "Disorder in the Courts" (archive).

<sup>6</sup> For those interested in the full conspiracy account, far worse than one might imagine, please see the entire story at <http://www.speakeasy.org/wfp/08/Boeing1.html>.

<sup>7</sup> On sick roles and chronic illness, see Charmaz 1991.

millions of dollars in litigation. In this climate, the role of social constructionist arguments – that an illness is defined or manifested socially – often serve the conservative function of denying that the illnesses “really” exist, and preventing any resources from being allocated to those suffering. The problem is that there are too many answers but no consensus on the questions.

For example, at a 1994 conference on MCS attended by almost all of the major players on both sides of the Boeing case, one researcher presented a paper that first dismissed the possibility that MCS was "real" and then proceeded to argue that MCS symptoms were quite possibly the result of worker-management tensions.

Poor worker-management relations, interpersonal conflict at home, and other forms of stress or pressure can exacerbate physical symptoms. People in settings where they are unable to directly address the causes of their tension may be forced to look elsewhere to define their symptoms. For example, a person who has a specialized job with an abusive boss may not be able to acknowledge the tremendous tension brought about by his/her boss. *An alternative label for this tension might be illness or MCS* (Pennebaker 1994: 505-7, emphasis added).

Significantly, Pennebaker is making an argument that is structurally identical to the one made by medical anthropologist Arthur Kleinman in *Social Origins of Distress and Disease* (1986). Kleinman argues that for many Chinese patients with neurasthenia, the mental, emotional and physical abuse they suffered during the Cultural Revolution may be the cause. The illness is may be the manifestation of this abuse. Practically, however, the implications for these two views are opposed. Neurasthenia in China during Kleinman’s fieldwork is considered by the state and general population as a real illness, and the abuse-as-illness receives sympathy and treatment, including compensation and rest. Pennebaker’s analysis, however – speculative rather than empirical – reduces MCS to "nothing but stress" and thereby specifically disallows any but the most rudimentary care and little sympathy. Shadowing Pennebaker’s statements is the clear implication that these supposed MCS sufferers are faking it.

Parallel to Pennebaker, the Boeing-paid psychologist Gregory Simon calls for an end to psychiatric studies including brain scans, “because they confuse the issue.” He is apparently respecting the notion that mental illness categories can do more harm than good for those saddled with them. He then declares that the current political-legal-economic climate precluded objective research on MCS:

Current policies for compensating liability and disability claims are a definite impediment to research on neuropsychiatric aspects of chemical sensitivity. In many cases, toxic mechanisms of injury are compensable while behavioral mechanisms are not. Given these policies, most patients and treating clinicians have strong incentives to emphasize neurotoxicity as the explanation for symptoms of anxiety and depression. Employers, insurers, and industry have equally strong incentives to emphasize behavioral mechanisms or preexisting psychopathology in order to reduce costs of compensation. Those with vested interest may overinterpret research data on psychiatric symptoms in chemical sensitivity as proving or disproving particular theories of pathophysiology. This political environment leaves little room for impartial research (G. Simon 1994: 494).

A cynical reading of this incisive passage is that it seeks to sustain current uncertainty over the status of MCS, denigrating existing SPECT studies along with Simon's own psychological studies. Such a strategy, if it succeeded, would thus continue to prevent MCS sufferers from obtaining "objective" proof of and compensation for their condition, especially since further research is not being pursued. As Buck Cameron, a member of the L&I pointed out:

[Boeing's in-house Health and Safety] Institute is supposed to be studying the possible connections between the symptoms of sick workers and chemicals used in Boeing plants. So far, it hasn't happened. (Nelson & Worth 1994: 14).

Nelson and Worth also quote Meg Much, a former worker at the Institute, "The company is not interested in making that link...When you get down to finding scientific evidence, nobody wants to do it" (14). These lines are drawn as follows: on one hand, the MCS sufferers are arguing that the preliminary evidence suggests (1) a need for further study, and (2) in the meantime, they should get the benefit of the doubt and some compassion and treatment. On the other hand, Boeing seems to be arguing that (1) in the absence of definitive (not preliminary) proof, it should not have do anything; and (2) it has a right not to pursue research that risks its own financial loss.<sup>8</sup> The issue of companies and possibly governments or societies not wanting to research risks raises the issue of the right not to know. Though it may seem wrong to connect the issue of corporate knowledge with that of individuals at genetic risk for an illness (such as Huntington's), even unions representing workers are wary of the potential bankrupting of a company that employs hundreds of thousands of workers. Similarly, sympathetic research scientists within large companies must attend to the legal ramifications of their research.

...The concern about the litigation consequences of doing research, from the law side of our corporation [a chemical industry carpet manufacturer], is a major stumbling block. I think that maybe, after looking at some well-conceived research protocols with good design, we scientist types can try and be persuasive to the legal types who are hysterical about it, and see if we can get them down off the chandelier (Dr. Hancey, quoted in TIH 1994: 659).

In the absence of industry-funded research, and recognizing the meager, underfunded studies of MCS, sufferers are left in the dark as to where to go next. These passages point to the fundamental situation wherein money, explanations, research and theories become aligned and in opposition to each other. Wittgenstein's implication in the epigraph to this section is that people

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<sup>8</sup> As the recent scandals regarding Tobacco companies cynically show, it would have been better for those companies not to have conducted studies of cancer links in the first place, than to have done so and hidden them.

might come to blows where there is no agreement on forms of life and the language used to define the rules. "If language is to be a means of communication there must be agreement not only in definitions but also (queer as this may sound) in judgments" (Wittgenstein, PI §242). Each of the new sociomedical disorders involves a struggle towards a new language and for the establishment of a form of life of suffering from the disorder.

In the Boeing struggle, the scans are like words whose rules of usage are unclear and unsettled because the forms of life -- the rules and judgements -- are not agreed upon. Each institutional site -- a doctor's office, an insurance agency, a health institute, a court -- becomes a place where rules and judgements are made, not simply obeyed. These rules include what tests count as objective evidence. These judgements include whether or not a particular disease is worth studying. One consequence of this is that these non-scientific locations become local obligatory passage points for what counts as the facts of the matter.

## Geography is Elsewhere

*... Biopolitical modes of fields of power are those which determine what counts in public life, what counts as a citizen, and so on. We cannot escape the salience of the biological discourses for determining life chances in the world -- who's going to live and die, things like that...*

-- Donna Haraway, interview<sup>9</sup>

I would like to use Donna Haraway's (1986) notion that geography is elsewhere to cut through the idea that facts can be settled in one place and be true once and for all everywhere. Rather, I think, it is often the case that the meaning of an event locally is decided somewhere else, that facts settled in one place are not settled in others, and that the venue of adjudication is often more important than the evidence available. In the case of the new sociomedical disorders, I am proposing that the reality of these illnesses as biological diseases is not settled by looking toward

the geography of the brain, but elsewhere, in disability courts, insurance companies, and individual doctors' offices.

The Boeing/MCS case is not the only time when legal-insurance adjudication takes over the definition of illness and disease. Many health care regulations unfortunately still adhere to a refusal to take mental illness seriously and contain a profound suspicion of malingering. Benefits for mental illness are often restricted in terms of time and cost. Recent research, especially brain imaging and genetics that demonstrate the biological nature of mental illness have been creatively used by sufferers and their families. For instance:

In the first case of its type, a father sued Arkansas Blue Cross and Blue Shield for increased coverage for the care of his daughter, who was hospitalized for bipolar disorder. His insurance policy provided for extensive coverage for physical conditions but limited coverage for 'mental, psychiatric, or nervous' disorders. The plaintiff argued that bipolar disorder is a biological disorder and therefore should be considered 'physical' under the terms of the policy. In this case, *Arkansas Blue Cross and Blue Shield v. Doe*, the courts ruled that bipolar disorder 'is a physical condition within the meaning of the Blue Cross contract.'" (OTA 1992: 161-2).

The institutional response to this litigation is perhaps predictable. After the court found in favor of the father, Blue Cross and Blue Shield rewrote their contract so that it explicitly defined Bipolar Disorder as a mental and not physical illness. In this case, contract law allows Blue Cross to make a list of what they will count as mental illness and include Bipolar Disorder on it. They can then cover it as such, regardless of popular or scientific definitions. Since another insurance carrier might treat bipolar as a physical illness, it is clear that 'facts' such as whether

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<sup>9</sup> Penley and Ross 1986.

bipolar is physical or mental are not simply discovered and then universally known. Rather, they are quite unevenly known and even the criteria of proof can vary from site to site.

With regard to the new sociomedical disorders, these varieties of factual status are multiplied again by the different state-level and administrative court systems. Shelia Jasanoff (1995), for instance, has persuasively demonstrated that legal notions of scientific proof, consensus and implication differ considerably from most scientists' notions. Moreover, alongside with Nelkin and Tancredi (1988), she has shown that (1) the courts' definition of scientific truth is historically variable and (2) it has tended toward a greater and greater emphasis on "hard," objective, neutral and automatically generated evidence (cf. Dumit 1995: ch.5). At the administrative level, for instance, the office of Housing and Urban Development (HUD) and the Social Security Administration (SSA) have already declared MCS as a kind of disability under the 1980 Americans with Disabilities Act (ADA), thus allowing MCS sufferers the right to live in toxic-free environments (Frisch 1994: 4). But disability law judges, like criminal court judges demand objective findings, especially with emerging illnesses (Heuser, Wojdani & Heuser 1991; Cheney & Lapp 1993). The relative autonomy of each administrative agency – SSA, HUD, insurance, HMO, Worker's Comp – and the fragmentation between federal and state authority in the U.S. creates a variegated landscape of opportunity and frustration for all parties involved in delimiting these sociomedical disorders.

For sufferers and their families, this landscape of differential diagnosis can provide an opportunity for them to help control the answers by *changing the venue* where the questions are asked. Biological definitions, especially the demonstrative proof of brain imaging provides the objective basis for declaring a kind of kinship among sufferers. Similar to the genetic diseases Rabinow (1992) has discussed, each of the sociomedical disorders has its own organized support groups, lobbying efforts and other institutional forms for communicating and advocating kinship based on objectively shared biological attributes. Once organized, even in very loose networks, they are able to share strategies and tactics for responding to a generalized cultural and

bureaucratic unwillingness to acknowledge their suffering. The internet, for instance, is one of the key sites for this kind of dispersed organization.

For example, a 1990 Zametkin, et al. article showing brain abnormalities with PET in ADD adults sparked the construction of a CompuServe Forum dedicated to ADD that went online in 1993. It was immediately a huge success with 7000 members in eight months and over 200 messages a day (Schwartz 1995). To provide some sense of the scale of this kind of interaction, the USENET online newsgroup <alt.med.cfs> (for CFS sufferers) received over 54,000 messages during the two years from mid-1995 to mid-1997. During that same time, the <alt.med.adhd> newsgroup (for attention deficit disorder) received over 74,000 messages.<sup>10</sup> Each of the other disorders also has many other online support forums as well as more formal organizations.

The internet, in these cases, provides a means for geographically dispersed sufferers to asynchronously share not only experiences, news, references, and resources, but also *strategies* for dealing with physicians, insurance, HMOs, and other bureaucracies. One internet file, for instance, notes that sufferers of CFS in Canada can use SPECT findings of brain abnormalities to obtain a diagnosis of Major Acquired Brain Dysfunction, which insurers will pay for, rather than CFS which insurers do not cover (Carpman 1993a: 2). Another source of information distribution is the Frequently-Asked-Questions document (FAQ). The FAQ for CFS runs some 35 pages and is updated approximately every three months (Burns 1996). It includes a pointer to explicit instructions on "Dealing with Doctors When You Have CFS" (Cracchiolo 1995).<sup>11</sup> This document instructs a sufferer in how to do homework on the condition and have citations and xeroxed articles organized and handy for the visit. It also suggests that one should remember that

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<sup>10</sup> USENET is divided into a hierarchy of thousands of newsgroups. *All* of these newsgroup messages may currently be accessed (for free) at the Dejanews website, <http://dejanews.com>. I am currently analyzing the entire set of these messages from both groups with the assistance of Warren Sack, MIT Media Lab.

<sup>11</sup> To acquire this document, send the message GET CFS HANDLER as email to <LISTSERV@SJUVM.STJOHNS.EDU>.

one may need to make a legal case for disability and therefore may be dependent upon the doctor's positive evaluation of one's illness; one should dress well because this will help avoid being diagnosed as having Major Depression; and in general one should treat the meeting as a business meeting between equals rather than as a helpless patient dealing with an omniscient doctor. This document and many others circulated through support groups, on and off the internet, help sufferers to take control of their identities and their medical interactions. Other methods of disrupting the normal authority and business-as-usual of the biomedical community by support groups and illness organizations include attending medical research conferences as patients, and sponsoring conferences themselves (Burns 1994: 3-4).

In sum, because the geography of facts regarding the new sociomedical disorders does not lie within the bodies of those afflicted, nor within the authority of their doctors, sufferers have necessarily become activists. They have, in other words, been forced to actively advocate for the evidence of their illness in non-traditional medical settings: courtrooms, insurance offices, the mass media, and the internet. In the next section, I focus on the science and technology of brain imaging in order to point to both its immense value to our understanding of the brain and its power in presenting apparently unambiguous images of different kinds of brains. At issue are the meanings ascribed to these images by different groups in non-traditional medical and scientific settings where the explanations of these illnesses (temporarily) rest.

## **State of the Art Neuroscience and Controversy**

*[Even a teacher is not able to recognize exactly when a young child begins to read.] But isn't that only because of our too slight acquaintance with what goes on in the brain and the nervous system? If we had a more accurate knowledge of these things we should see what connexions were established by the training, and then we should be able to say when we looked into his brain: 'Now he has read this word, now the reading connexion has been set up.' – And it presumably must*

*be like that – for otherwise how could we be so sure that there was such a connexion [in the brain]? That it is so is presumably a priori – or is it only probable? And how probable is it? Now ask yourself: what you know about these things? -- But if it is a priori, that means that it is a form of account which is very convincing to us. – Wittgenstein, PI §158*

Wittgenstein was fascinated with our apparent fixation on the idea that the head is the site of thinking and feeling, and that the brain as the site where answers to our human nature will be found. In this passage he addresses the fact that we appear to *know* that if we just had the right technology, we could determine from someone's brain patterns exactly what he or she was doing, thinking and feeling. Those who suffer with these conditions are put in the terrible position of having to contest bureaucracies and physicians as well as their friends, families and their own self-doubts. Even attaching a name to a set of symptoms is helpful and often therapeutic as it allows one to *have* a disease and not simply experience mysterious and troubling symptoms.<sup>12</sup> Brain imaging offers the promise of *showing* that the disorder really is in their brain and not in their heads.

PET scanning and its less expensive cousin SPECT are recent technologies that produce images of living brain and body functions through the use of radioactive tracers.<sup>13</sup> Unlike CT (computed tomography) and MR (magnetic resonance), which provide images of the tissue and structure of the brain, PET and SPECT promises to provide images of the living brain in action, as it thinks, worries, gets sad, adds and goes mad. These functional imaging techniques represent a new paradigm in diagnosis and visualization, producing high resolution *functional* images through computer power.

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<sup>12</sup> See Dumit 1997.

<sup>13</sup> The acronym PET derives from PETT (positron emission transaxial tomography) developed at Washington University around 1974 (Dumit 1998).

There are many excellent sources for descriptions of how PET works (Posner & Raichle 1994; Roland 1993). The following brief description is intended to gesture toward the complexity of the process as both difficult and amazing. After an experiment is designed and representative subjects selected, radioactive isotopes must be obtained.<sup>14</sup> These isotopes are short-lived, their half-lives are from two minutes to two hours. They are immediately "tagged" or attached onto other chemicals to form radio-labeled substances, or radiopharmaceuticals. Flourine-18, for instance, can be tagged onto glucose, and Oxygen-15 can be tagged onto water. These radiopharmaceuticals thus either mimic or are analogs of substances regularly circulating through the brain.

The next step is to set up the experiment, inject the person with the radiopharmaceutical, and place them in the scanner. While the person carries out some task (such as looking at words) or attempting to maintain some state (such as rest or anxiety), his or her brain is assumed to be using energy differentially in those regions involved in that activity or state. Scans can be taken quickly for a "picture" of blood flow during a thirty second period, or they are taken after forty minutes for a "picture" of the glucose utilization up to the scan.

As the radiopharmaceutical decays in the brain, it emits particles that travel in relatively straight lines. The scanner consists of a ring of detectors connected to a computing system that reacts when they are struck by the particles. After collecting hundreds of thousands of data points, the computer attempts mathematically to reconstruct the approximate spatial density of the radiopharmaceutical, a process involving many assumptions about brain biochemistry and metabolism. The result is a simultaneously simple (in the sense of transparent) and complex image of a subject's brain at work.<sup>15</sup>

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<sup>14</sup> With PET, a small but expensive and labor intensive cyclotron is needed to produce special isotopes.

<sup>15</sup> There are many other uses of PET that deal with other organs (e.g., heart, lungs, liver), and with cancer.

The use of PET to study the brain in action is a source of continuing controversy not because the technology is under almost continual revision, but because the referents of the images, theories of human behavior, of human cognition, and of how the human brain actually works are themselves sites of controversy.<sup>16</sup> Functional brain imaging studies have therefore been described as hypothesis generating rather than hypothesis confirming (Rapoport 1991). Nonetheless, the information that is provided by functional means is, quite simply, unavailable by other means, and certainly, any attempt to theorize the brain and cognition must be accountable to the results of such studies.

In addition to studying the history and community of functional brain imaging, however, I have also concentrated on *how* notions of brains and meaningful brain images come to be known outside of the relatively small group of biomedical researchers. To rephrase Wittgenstein: *How*, as a culture, do we come to know about these things? This question is vital since as Wittgenstein pointed out: if the result of our learning about brains and imaging technologies is as if *a priori*, then these are "a form of account which is very convincing to us." Consequently, as an ethnographer, in addition to fieldwork in PET scan laboratories, interviewing researchers and graduate students, and attending imaging conferences, I also studied the role of brain scans in popular culture, in courtrooms, and in the lives of those whose illnesses are presumed or suspected to lie in their heads.

One clear finding was that throughout these heterogeneous social worlds, the details behind the experiments were often left behind, and what remained was almost always two images, with ideal labels like "depressed person" and "normal control." In many cases, these labels were reduced to one word each: "depression" and "normal." The images thus appear to collapse a symptom – a brain abnormality correlated with a diagnosis of depression – into a referent – a depressed brain, or a depressed person.

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<sup>16</sup> See Poeppel 1991 and responses, and Gazzaniga 1997 for examples of some serious

This visually reductive practice, however, is not limited to popular culture. Researchers using PET almost exclusively conduct their studies on relatively small sample sizes (4-20 persons) and if they discover statistically significant differences between brain regions in sample versus controls, they report these numerical findings. In their scientific articles they also usually *show only two* images (or sets of images) that are almost always the most extremely different images. This provides a crystal clear visual referent implying diagnostic discrimination, even when the text of the article explicitly warns against it. This practice of showing extreme images even when the normal distributions of the two groups overlaps considerably is standard practice within the brain imaging community and within the life sciences in general. As one researcher stated to me:

If you are honestly and forthrightly trying to show something in the article, you try and take the data and the images and process them to point that what you know to be true you can see. So we take the extreme cases for the readers to be able to see them. You have the tabulated data to look at all cases. It is fine.

(Michael Phelps, interviewed in Dumit 1995: 168).

The risk of such practices, of course, is that the images will travel without their accompanying graphs and caveats, and stand alone as visual arguments of the existence and extreme difference of one *kind* of person or brain state from another. In my previous work, I have treated this risk as a negative, as risking mistaking the scan -- a statistical product -- for diagnosis and kind of person. I repeat this argument here because in the case of mental illnesses and the new sociomedical disorders it is precisely this risk which sufferers are willing to take: they would prefer to be stereotyped biologically and to risk misdiagnosis rather than being excluded from diagnostics altogether. The alternative -- that there is not yet enough evidence to decide one way

or another regarding the reality and significance of their illness and therefore they should wait -- is simply not livable given the current state of healthcare in the U.S.

Functional brain imaging, because of its construction as a device that shows differences between groups, plays a pivotal role in almost all of these new sociomedical disorders. Its advantage is that it not only provides statistically correlated differences between affected populations and normals, but it can "show that difference." Further, as opposed to graphs and other forms of visual displays of quantitative data, functional brain imaging is presented as a combination photograph and map of a person's or persons' brain in action. Photographically, it appears as an objective snapshot unmediated by subjective impressions or manipulations. Cartographically, it points out specific areas of the brain that are not functioning normally, areas already mapped as relating to attention, memory, decision making and so on. Together, these two discourses imply that a functional brain image not only shows the disorder itself (demonstrating its existence in general and within that particular brain or brains), but also show how it works (and therefore how it might be treated). Finally, within a biomedical culture, the demonstration that a disorder is in the brain implies that it is not (solely) in the mind. The brain in this sense can serve as etiology: e.g. a "brain-caused illness."

My contribution to this literature here is to survey the volatile, meaningful roles of brain imaging within the ongoing histories of these conditions. Brain imaging functions within each disorder as a "gold standard" of demonstrative proof of neurobiological involvement (Carpman 1993a: 2), and also serves as a site for the intertwining of these various disorders. A 'gold standard' in medical terminology is traditionally associated with a test that definitively identifies a biological marker for a disease (cf. Aronowitz 1998). In the case of the new sociomedical disorders, brain images repeatedly are taken from preliminary studies and iconically used as proof of the neurobiological nature and even cause of these conditions. The easy migration of this *basic* research in brain function and pathophysiology to the diagnosis and promotion of new

disease categories is a function of the visual persuasiveness of brain images, one that is unmatched among other diagnostic tests.

Brain imaging scans are used as critical arguments by communities of all of the different sociomedical disorders. The scans for each illness are often done by the same relatively small group of researchers, and the larger imaging community is quite divided over the applicability and appropriateness of this use of scanning, with most researchers opposed. Significantly, those opposed most often have nothing at all to say about the application of brain imaging to these disorders. They would, quite simply, prefer the disorders not be studied at all with brain imaging. At best, they would prefer to wait until there is some agreement on precisely what a given disorder is, and some sense of its etiology. But again, for sufferers who see little mainstream attempt to put these disorders into research budgets, exploratory and peripheral research is preferable to no research at all. In the following, final section, I trace some of this preliminary brain scan research on these sociomedical disorders as it is restricted by research budgets and specific cultures of meaning and accusation.

## **Good-enough Science and Political Economy**

*A picture is conjured up which seems to fix the sense unambiguously. The actual use, compared with that suggested by the picture, seems like something muddled...*

– Wittgenstein, *PI* §426

Despite the small number of studies conducted on these sociomedical disorders, and despite being preliminary and underfunded, these brain images are powerful across social and cultural boundaries: they serve as insurance arguments, self-help diagnoses, legal claims for reparations, and popular arguments against the stigma of mental illnesses. And control of these images is most definitely not in the hands of the researchers who produce them.

Since there are not unlimited resources and money for labs and research, determining what to study is itself a social, political and economic issue. Not only must each disease or disorder

compete with every other one for resources, so must each research method compete within each disorder. Consequently, one of the functions of national support groups is advocating for more research money for that particular disorder and for specific research directions.<sup>17</sup> Encouraging research into the neurobiological substrates and causes of mental illness, for instance, has been one of NAMI's chief tasks. With regard to the new sociomedical disorders, there are precious few federally funded research studies at large, central research universities. Thus, the 'debate' over brain imaging studies does not take place 'in science' between mainstream and peripheral researchers, but across a purported science / non-science divide.<sup>18</sup>

Mental illness activist communities, for instance, such as the National Alliance for the Mentally Ill (NAMI), have heavily supported and promoted functional brain imaging studies among other investigations into the biological basis of mental illness (e.g. genetics). They do this in direct response to a continuing stigma attached to mental illness, and a continuing history of reluctance by the state, communities and insurance agencies to adequately treat those suffering from it. Thus, not only do these studies offer the hope of designing specific psychopharmacological therapies (by identifying the particular brain areas affected by the illness), but they also visually demonstrate that specific mental illnesses such as depression are real neurobiological disorders. The Office of Technology Assessment book, *The Biology of Mental Disorders* sums up this argument:

Given that family members are often viewed as the agents of mental illness, it is understandable that they embrace biological theories of mental disorders. When families belonging to the National Alliance for the Mentally Ill (NAMI) were

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<sup>17</sup> *Fortune* magazine recently ran three articles describing men coming to terms with prostate cancer and actively intervening in treatment decisions. One of the articles lamented the relative paucity of research dollars into prostate cancer relative to breast cancer. It cited efforts by men to emulate women's successful organizing around breast cancer, to the extent of hiring the some of the same women to agitate for prostate cancer (*Fortune* 1996).

<sup>18</sup> See studies of pseudoscience and other controversies (e.g., Wallis 1979).

asked what had helped them to cope with stigma, 73.2 percent indicated that “research findings which establish a biological basis for mental illness helped much or very much in dealing with stigma”. The concept that a biological defect causes a mental disorder largely exonerates family members and the individuals themselves from blame, placing it instead on a disease process (OTA 1992: 160).

Extreme brain images can also be used to redirect blame for criminal acts. In courtrooms, extreme images have been used to argue insanity defenses on the basis of a defendant’s scan being more similar to published scans of schizophrenics, for instance, than published normals. Even though the peer review literature exclusively argues that in spite of the statistically significant correlates of certain brain features and schizophrenia, there is *no possibility* for going backward from scan to diagnosis, the visual argument presented in the form of the images remained compelling. The nature of this persuasion has been described by Zatz, who is referring to colored graphs:

"Such 'painting by numbers,' Zatz contended, can have a tremendous impact [on juries]: 'This is powerful testimony. It is simple, it is dramatic, and it is unforgettable. It makes allegedly subclinical injury almost visible to a jury that has come to expect a look at the amputated leg, a glimpse of the burnt flesh, a living reminder of a mistake in plastic surgery, or the proverbial x-ray of the surgical tool left inside the body. Practically speaking, it leaves the defense with an awful lot of explaining to do.' ..Represented by dots in a chart, test outcomes become mute 'eyewitnesses' to actual events” (Jasanoff 1995: 128-9, citing Zatz 1987).

With functional brain images, one is really “seeing the burnt flesh,” a lesion in the brain is often made to appear as a black area in the scan, or a "hole." Some functional techniques consist in counting the 'holes' in the brain. It must be noted that the use of images in courtrooms persists in spite of the furious opposition of over 90% of the imaging community (Mayberg 1992; Dumit

1995). It should be clear from these short descriptions of the roles of brain images of mental illnesses, however, that their status and their uses outside of laboratories is anything but settled (; Kulynych 1997).

Surveying the available literature on sociomedical disorders, one is immediately struck by the ubiquity of compelling brain images. The Office of Technology Assessment's study of *The Biology of Mental Disorders* contains PET images for almost every mental disorder category (OTA 1992). The oversized CFS conference book, *The Clinical and Scientific Basis of M.E./CFS*, has PET, SPECT, EEG and MRI scans on its cover (Hyde et al. 1992). And, the NIMH booklet on ADHD has only one scientific image (NIMH 1994). It contains two PET scans, ADHD vs. Normal. These scans are from the 1990 study by Zametkin et al., a study that Zametkin later failed to replicate and suggesting that the 1990 study was probably a false positive.

The underfunding of research into these sociomedical disorders has resulted in many cross studies and low sample sizes. Researchers using functional brain imaging often study more than one of the disorders and either attempt to show that there are distinct differences between them, or argue that some disorders are variations of other ones. On the basis of SPECT brain pattern similarities, for instance, Staudenmeyer (1995) claimed that CFS was really depression. Komaroff and other researchers, however, counted defects in SPECT images among patient groups and distinguished CFS, dementia and depression (Carpman 1993a: 7). Heuser et al. used SPECT to distinguish between MCS, CFS and depression (Heuser et al. 1993; TIH 1994: 570). In other studies, one third of CFS patients have been found to be chemically sensitive, as have many sufferers of Gulf War Syndrome (Deluca 1994: 513; T. Simon 1994: 573). A preliminary study of GWS with SPECT found six out of six patients had central nervous system damage. Many veterans of the Gulf War who are frustrated with their treatment by the Department of Veterans' Administration find outside MCS physicians who diagnose MCS (Miller 1994: 256). Major General Ronald Blanck, who has investigated GWS with SPECT, found it similar to CFS (even though the Department of Defense will not consider MCS or CFS as valid diagnoses) (Burns

1994: 10; Gulf War Org 1995: 2). Jay Goldstein and Theodore Simon, two prominent SPECT researchers, have each studied breast implant silicone toxicity in addition to MCS and CFS (Carpman 1993b: 2; TIH 1994: 599). Regarding ADD, based on SPECT hypoperfusion patterns, Dr. Michael Goldberg hypothesized that many ADD children should really be diagnosed with CFS. He suggested that the widened DSM-IV category of ADD, which now includes an "ADD-quiet" subtype is causing misdiagnoses (Carpman 1993a: 2,6). This widespread cross-fertilization of brain imaging and brain theorizing often helps define and certify or decertify more than one sociomedical disorder at the same time.

For most sufferers, a single brain imaging study with statistical significance is more than enough proof that their disorder is not only real, but brain-based and neurobiological. This is especially true when the study shows an abnormal scan of a patient looking very different from a "normal" scan of a healthy individual. The Zametkin et al. PET study of ADD adults, cited above, has been characterized in the magazine *Wired* by a psychiatric researcher as providing "credibility for the adult form [of ADD]" (Schwartz 1995).<sup>19</sup> *Wired* continues, "Since the article was published, there has been a growing awareness of adult ADD in the medical community. And thousands of adults with attention problems have been coming out of the closet." Other sources refer to "the classic Zametkin study" (Diaz 1994:4) as "the first clear evidence of a neurobiological difference between hyperactive and normal subjects" (Runge & Jaffe 1996). The visual impact of PET scanning thus plays directly into the metaphors of proof such that evidence becomes clear with it.

Likewise, for CFS, a series of SPECT studies by Mena et al., found 70% of sufferers had abnormalities in their brains. These studies are cited as "breakthroughs... referenced by nearly all researchers" (Carpman 1993a). Among these studies is one which showed that CFS was different from depression based on different patterns of brain abnormalities. "These data should end all

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<sup>19</sup> Schwartz uses the acronym ADHD.

speculation about CFS being a psycho-neurotic disease" (Wellness Web 1994). These claims are made in the face of only preliminary, and often underfunded studies. For instance, Paul Levine, an advocate for CFS, declared that "neural imaging as a whole is definitely showing abnormalities in CFS patients. Neural imaging techniques are being refined and are very promising, but they're not yet ready for clinical application" (Ibid). In these sentences he stakes out a specific notion of objectivity for sufferers that allows definite *existence* of the disorder to be established based on these early mapping studies. Levine further characterizes the location of these disorders as *in the brain* while maintaining that the studies do not provide any diagnostic utility. This is a form of objectivity alien to most mainstream researchers who typically study conditions already known to exist in the brain. It is as also a form of objectivity unfamiliar to many readers of this chapter.

With regard to this preliminary research however, there are many researchers who would like to keep the questions open while not jumping to any premature conclusions (Posner & Raichle 1994). Dr. Helen Mayberg, who attended the TIH conference as a respected mainstream PET researcher and neurologist, for example, urged caution with regard to the use of SPECT scans in MCS and CFS on the basis of the SPECT results being non-specific: what the scans show looks like more than one disease at the same time and is specific to none. She also noted that the apparent percent of abnormalities claimed to be found in sufferers (approximately 90%) is better than even the most well-characterized diseases such as epilepsy (70-80%), raising questions regarding the meaning of the results. Finally, she notes that since there is no pathophysiology known for MCS, there is no hypothesis being tested. She cautions that SPECT is therefore only useful for research, not diagnosis and that it is not appropriate for use in court (Mayberg 1994: 600).

A question thus arises: Are these preliminary underfunded studies, which are touted as proof, "bad science"? Are interest groups pressing for specific research agendas biasing otherwise objective work? Or, is it possible that there is a *need* for public relations research promoting these

disorders as "brain disorders"? (OTA 1992; ADHD Guide). Decisions as to what is important to study, and for whom, are made at many different levels of public culture, including Congress, the NIH, and corporate funders. These decisions determine much of what truths get produced. Peripheral, underfunded science is not necessarily "bad science" but it is often "less good", less resourceful, even less rigorous (in no small part due to older machines, less sophisticated computers, smaller sample sizes). For purposes of advocacy, however, and keeping open questions that are not yet answered, these underfunded images look just as good and rigorous as the highly funded ones. These political and economic disadvantages produce worlds where truth is not unitary, nor simply hierarchical, but quite uneven.

If I want to underscore anything in this paper, it is this unevenness of objectivity, truth and meaning. Recalling for a moment the father who sued Blue Cross and Blue Shield, I want to call attention to the fact that despite the current state of BC/BS contracts that define bipolar disorder as a mental illness, the father's lawsuit nonetheless reconfigured the meaning and status of bipolar disorder *locally and temporarily*. It is quite possible, I suggest, that these temporary resting states of varying lengths of time are a much better empirical description of "truth" than atemporal, universal ones whose adjudication is not made clear. What good does a paper or study do that claims to have objective evidence that bipolar disorder is physical, if BC/BS does not have to listen, and a sufferer gets less treatment?

By unpacking the layers of conflicted judgements and experiences surrounding these sociomedical disorders, we can begin to understand how scientific and medical statements come to be central and yet non-decisive in many settings. Brain imaging -- arguably the most ambiguously promising diagnostic technology -- has and will continue to play a key role in resisting the easy assignment of blame, stigma, and causation to the individual. But it appears that it will not do so by settling the matter once and for all in biology. Rather, the continual jostling of competing social, political and moral notions of nature and personhood that underpin

our notions of biology and disease imply that these sociomedical disorders might only be "explained" temporarily and locally.

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